

Shopping around the internet today and tomorrow: towards the millennium of cybermedicine

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"The world wide web is the universe of network-accessible information, the embodiment of human knowledge" (W3C)

The evolution of the "information age" in medicine is mirrored in the exponential growth of medical web pages, increasing numbers of databases accessible on line, and expanding services and publications available on the internet. The handful of computers linked by the predecessor of the internet in 1969 has grown to more than 5 million websites today. In spring 1998, the world wide web had at least 320 million web pages of general content.¹ In addition, there are countless conversational areas on the internet, like chat rooms and newsgroups, where people exchange messages on tens of thousands of subjects. Somewhere more than 150 million people currently communicate over the internet.² According to the World Wide Web Consortium (W3C), however, the rapid "hypergrowth" of the web from 1992 to mid-1995 has now somewhat slowed to roughly gaining an order of magnitude "only" every 30 months.³

Summary points

More than 100 000 medical websites exist, and their number is still growing rapidly

"Cybermedicine" is a new academic specialty at the crossroads of medical informatics and public health, studying applications of the internet and global networking technologies to medicine and public health, examining the impact and implications of the internet, and evaluating opportunities and the challenges for health care

The internet revolution in health care is largely driven by a massive consumer demand for online health resources

The fact that patients have access to the same databases as clinicians leads to increased consumer knowledge, which is pushing clinicians to higher quality standards and evidence based medicine

Patient to patient interchanges are becoming an important part of health care and redefine the traditional model of preventive medicine and health promotion

Problems of cybermedicine include the quality of online information, lack of standards, and lack of social equity

daily.⁴ An interesting observation from this and other surveys⁵ is that health and medical content seems to be one of only a few categories on line that women are more likely to use than men.

No one knows the exact number of medical (including health and "wellness") websites, but the frequently cited figure of 15 000 health sites⁵ is probably an underestimate, given that Yahoo USA alone lists more than 19 000 websites under the topic "health,"⁶ and other international Yahoo catalogues together add roughly another 15 000 sites. Assuming conservatively that a maximum of 30% of all sites are registered in Yahoo,¹ we can estimate that there are a minimum of 100 000 health related websites available. Health information providers on the web include mostly private companies offering medical products or medical information (news services, electronic journals, databases), individual patients and health professionals, self support groups for patients, and professional associations, non-governmental organisations, universities, research institutes, and governmental agencies.

Cybermedicine: a definition

The developments outlined above probably have a considerable impact on efficiency and quality of future health care, consumer empowerment, public health, medical education, and several other issues. At the crossroads of medical informatics and public health a new academic specialty is emerging, "cybermedicine"—that is, "medicine in cyberspace," where "cyberspace" denotes the internet (fig 1). An arbitrary definition of this discipline could be "the science of applying internet and

Medical information is often said to be one of the most retrieved types of information on the web. In fact, according to a survey of October 1998, 27% of female and 15% of male internet users say that they access medical information weekly or

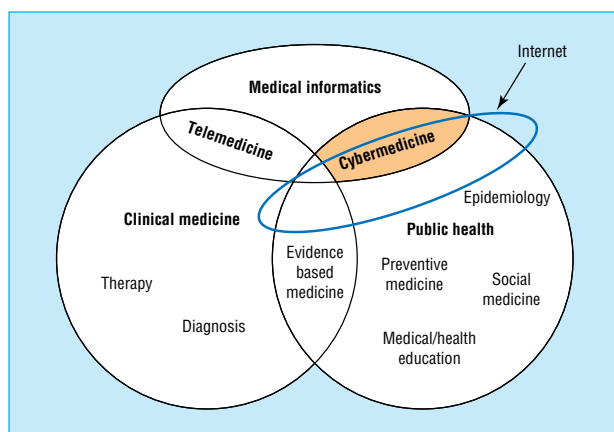


Fig 1 Definition of cybermedicine

global networking technologies to medicine and public health, of studying the impact and implications of the internet, and of evaluating opportunities and the challenges for health care.” Of particular interest in our unit for cybermedicine at the Department of Clinical Social Medicine in the University of Heidelberg is the exploration and exploitation of the internet for consumer health education, patient self support, professional medical education and research, the evaluation of the quality of medical information on the internet, the impact of the internet on the patient-physician relationship and quality of health care, and the use of global networking for evidence based medicine.

Cybermedicine is distinctive from telemedicine, although there are overlapping issues, especially as the internet can also be used as a medium for telemedical applications. While telemedicine focuses primarily on a restricted exchange of clinical, confidential data with a limited number of participants, for the most part between patient and physician or between physician and physician, in cybermedicine there is a global exchange of open, non-clinical information, mostly between patient and patient, sometimes between patient and physician, and between physician and physician (table 1). Telemedicine for the most part is applied to diagnostic and curative medicine, while cybermedicine is applied to preventive medicine and public health. The term “prevention” in this context covers not only measures to prevent the occurrence of disease (primary prevention)—for example, by health education on websites set up by professionals or consumers—but also the reduction of the consequences of disease (tertiary prevention)—for example, by information exchange among patients through newsgroups, websites, or via email, leading to improved self management of their diseases. In cybermedicine the new role of the consumer redefines the traditional concept of “prevention” and “health promotion” (that is, the process of enabling people to increase control over the determinants of health and thereby prevent disease or reduce the impact of disease), which traditionally implied a formal com-

munication process between the health professional as sender and the consumer as receiver, whereas on the internet, health promotion and prevention becomes largely a process between consumer and consumer.

Other people may have other definitions of cybermedicine. In his book *Cybermedicine: How Computing Empowers Doctors and Patients for Better Health Care*, Warner Slack uses this term in a much broader sense, not only focusing on the internet but referring to the use of computers in medicine in general.⁷ Another article, entitled “Cybermedicine” in the *New England Journal of Medicine*,⁸ merely referred to medical advice services on the internet and thus to only one aspect of what we think constitutes cybermedicine.

The role of consumers

While most physicians still lag behind other professions in their use of modern information technology (see, for example, the 1997 American Interactive Healthcare Professionals Survey by FIND/SVP⁹), in many parts of the industrialised world consumers have taken the lead in adopting new media for retrieving and exchanging health information. While telemedicine is often driven by a “technological push,” cybermedicine is characterised by a remarkable “consumer pull.”

We would argue that consumers and patients will have a crucial role in being a major driving force for clinicians to “go on line” as consumers accessing electronic information will inevitably increase the pressure on caregivers to use timely evidence and will force them to become acquainted with information technology. The internet is therefore a motor for evidence based medicine, not only because it provides an infrastructure for health professionals to access resources and databases¹⁰ but also because it allows consumers to draw from the same knowledge base, thereby increasing consumer involvement in health-care decision making and increasing the pressure on caregivers to deliver high quality health services.¹¹ It is mainly the latter aspect that is the true revolution (at the same time a challenge¹²) for health care. While it is still a matter of debate whether the typical patient can translate these possibilities directly into better health (rather than simply getting lost in a stew of information or becoming a “cyberhypocondriac”), many patients will use this information at least to challenge the evidence base of physicians by confronting them with “anecdotes” from the internet. This is often referred to as being one of the negative sides of medical information on the internet as it puts new strains on the patient-physician relationship, but we can also regard this as a positive incentive for doctors to learn how to use electronic evidence based resources. As physicians follow consumers into the information age this will further increase the demand and the provision of information on the internet, leading to even more consumer empowerment and patient centred and evidence based medicine—a positive feedback loop (fig 2).

Table 1 Telemedicine versus cybermedicine

| Detail | Telemedicine | Cybermedicine |
|-----------------------|--|---|
| Geographical coverage | Local or regional | Global |
| Application area | Primarily curative medicine | Primarily preventive medicine |
| Security | High security possible | Security limited |
| Data exchanged | Clinical data | Information for patient education and self support, anonymised clinical data for medical education, anonymised epidemiological and public health data |
| Exchange between | Patient-physician, physician-physician | Patient-patient, patient-physician, physician-physician |
| Aims | Monitor individual patients, diagnose, and treat | Prevention (especially primary and tertiary), health promotion, monitor populations, gather epidemiological and other data from patients, use patient feedback and consumer involvement for evidence based medicine |
| Driven by | Sometimes technological push | Mostly consumer pull |
| Setting | Controlled setting, limited number of well defined users | Uncontrolled conditions |
| Evaluation | Possible | Impact on populations difficult to measure |
| Reach | Reaching tens or hundreds | Reaching millions |

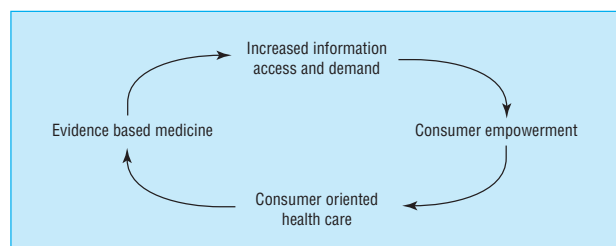


Fig 2 Positive feedback loop between the information age, consumer empowerment, and evidence based medicine

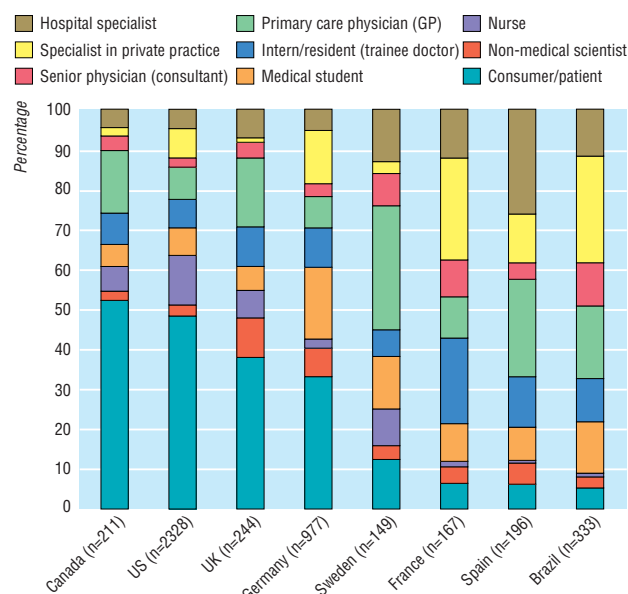


Fig 3 User profile of dermatology atlas website intended for health professionals

User demographics

At this point it should be emphasised that according to our own experiences¹³ considerable differences from country to country exist regarding the ratio of consumers to physicians shopping for medical information, indicating that data from the United States (which are predominant in the literature) must not necessarily be generalised to other countries.

Between July 1998 and February 1999 we conducted a internet based questionnaire survey among the users of our dermatology internet atlas website,¹⁴ which was answered by 6441 users from all over the world. (The advantage of doing such a survey on a medical website that primarily provides images is obviously that language bias can be minimised.) Figure 3 shows the distribution of the 4605 users from the eight countries that had the highest absolute number of users. Among them, Canada has the highest percentage of consumers, closely followed by the United States. In both countries consumers already outweigh healthcare professionals in using an internet resource primarily intended for medical professionals, contrary to countries such as Spain or Brazil, where users are largely health professionals.

We also observed differences from country to country concerning the relative proportion of the various health professional groups—for example:

- There was a relatively high proportion of general practitioners (as opposed to specialists) in Canada, the United Kingdom, and Sweden as opposed to a relatively high proportion of specialists in countries such as Germany, France, the United States, Spain, and Brazil. For Germany, the United States, and the United Kingdom these data correlate well with the actual ratio between specialists and general practitioners in the physician population of these countries¹⁵

- There was a relatively high proportion of hospital specialists in Canada, the United Kingdom, Spain, and Sweden as opposed to the preponderance of specialists in private practice in the United States, Germany, France, and Brazil. Again this partly reflects the actual ratio of specialists in private practice compared with the public sector in the respective country

- There was a relatively high proportion of nurses in the United States, Canada, the United Kingdom, and Sweden as opposed to virtually no information retrieving nurses in other countries, probably reflecting the differing roles and level of responsibility nurses have in these countries.

While these data have been collected in the specialty of dermatology and may be prone to self selection bias and therefore not be representative, they remind us that there are important differences among countries in internet use, not only because of technological factors such as internet access and penetration but also because of differences in healthcare systems as well as other cultural and sociological factors.

Quality issues and other problems

The quality of information is a critical factor for the use of cybermedicine for consumer empowerment, patient support, health education, and evidence based medicine. Pioneering studies that assessed the quality of websites¹⁶ and newsgroups¹⁷ or evaluated interactive venues by posing as a fictitious patient^{18,19} all showed that important aspects of quality such as reliability, accessibility, and completeness of information and advice found on the internet are extremely variable, ranging from the useful to the dangerous. While a similar problem is also known from traditional media such as magazines, newspapers, and television, the internet adds a new dimension because, firstly, everybody can be a publisher (often without any quality or editorial control at the stage of production), secondly, originators of messages and their credibility are difficult to assess for readers, and, thirdly, the line between editorial content and advertisements is often blurred. Organisations such as the Federal Trade Commission (FTC)²⁰ or the US Science Panel on Interactive Health Communication²¹ have repeatedly warned that much information on the web is misleading or positively harmful. Surveys also show that most internet users would like to be able to identify and filter potentially harmful information more easily.²² At the same time, it has been pointed out that many rating systems on the web are “incompletely developed instruments.”²³

But quality issues are not the only problems that have to be solved. Lack of standards are another concern. While internet protocols led to a global standardisation of how computers talk to each other, standardisation on many higher levels (such as medical applications) still has to be achieved to reach interoperability of medical internet resources.

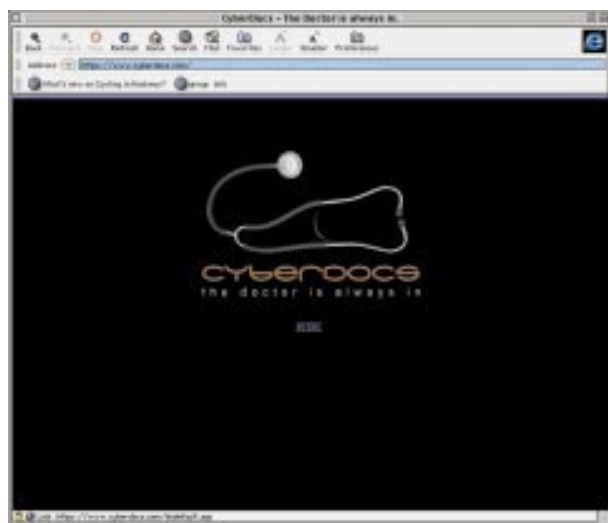
The third major challenge is less a technical but more a social issue: How can we avoid the global health network staying limited to the industrialised world and not reaching populations and areas that are most in need of improved health? This problem is not confined to developing countries, but even if we look at users of the internet in the “developed world,” where the internet is well established, ethnic minorities are underrepresented and low income as well as poor education remain real barriers to accessing health and medical content on line.⁵

Future developments: towards a universal medical knowledge base

The internet will change radically in the coming millennium. One major revolution on the web will be a “quantity leap,” freeing today’s internet from some of its technical limitations. The next generation internet (see www.ngi.gov) will operate at speeds up to a thousand times faster than today. Sight, sound, and even touch will be integrated through powerful computers, displays, and networks. Patients will be able to videoconference with their healthcare providers, security problems will be resolved, and the internet will increasingly be used for transmitting clinical data, linked with and integrated into educational resources.

Table 2 Arbitrary selection of websites that exemplify some aspects of “cybermedicine”

| Address | Details of access |
|---|--|
| Access to evidence, evidence based medicine | |
| www.ncbi.nlm.nih.gov/PubMed/ | Probably the most important address for physicians (and increasingly consumers) on the web: PubMed, one of NLMs gateways to Medline, features pre-Medline (bibliographic entries submitted directly from publishers) and links to other databases such as GENBANK or directly to the publisher's website if the article is available on line |
| www.guidelines.gov/ (USA) | Online accessible databases—many are still pretty much under construction—containing evidence based clinical practice guidelines—that is, systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances |
| www.show.scot.nhs.uk/sign/home.htm (Scotland) | |
| www.ihs.ox.ac.uk/guidelines/ (UK) | |
| www.cma.ca/cpgs/ (Canada) | |
| www.leitlinien.de/ (Germany) | |
| www.nzgg.org.nz/index.htm (New Zealand) | |
| www.mja.com.au/public/guides/guides.html (Australia) | |
| www.cochrane.org/ (Cochrane Collaboration) | |
| Patient-physician exchange | |
| mednet.stanford.edu/cgi-bin/medworld/HyperNews/get.cgi/patient.html | One example of an open online forum where patients and physicians can exchange experiences |
| www.cyberdocs.com/ | Example of a commercial “cyberdoc” |
| www.kwikmed.com/ | A more questionable form of cybermedicine—online prescribing of lifestyle drugs |
| Patient-patient exchange | |
| news:alt.support.cancer | Cancer support newsgroup |
| webhome.globalseve.net/hidecan/entrance.html | HIDE Network—website for people with hidradenitis suppurativa, just one example of self support groups organising themselves on the web |
| www.webring.org/ringworld/health/disease.html | Patients with various diseases, and their families, organise themselves in “web rings” |
| High quality cancer information | |
| www.oncolink.org/ | University of Pennsylvania Cancer Center Resource |
| cancernet.nci.nih.gov/ | Cancernet at US National Cancer Institute (NCI) |
| Low quality cancer information | |
| www.pilhar.com/English/english.htm | Cancer healer, Geerd Hamer |
| Search tools | |
| www.medmatrix.org/ | Medical Matrix—an internet catalogue |
| www.achoo.com/ | Another medical “catalogue” |
| www.hon.ch/MedHunt/ | MedHunt, a search engine |
| www.mwsearch.com/ | Medical World Search, another search engine |
| www.dr-antonius.de | Dr Antonius, a German search engine for medical information |



The second revolution will lead to a “quality leap.” Up to now, the web has been primarily used for human to human communication. The vision of the web, however, goes beyond this—the second side to the web, yet to emerge, is that of “machine understandable information.”²⁴ If this vision becomes reality in medicine, a part of the web would evolve into a global medical knowledge base that is browsable and searchable across languages and continents. Key to this development is the widespread use of metadata (medPICS/XML/RDF), which means linking human readable content with standard nomenclature such as the UMLS (Unified Medical Language System) and other descriptive and evaluative meta-information, either by authors themselves or by third parties.^{25–26} In such a global medical knowledge base, diverse medical internet applications and resources such as text, images, and retrieval systems of databases would then be interconnected beyond manual

“linking”—glued together by middleware and intelligent software agents, helping internet medical users to navigate in an unbounded information space. Together, these developments will once again revolutionise discovery and dissemination of knowledge in medicine.

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